

Use of Health-Related Online Sites

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Abstract

This report offers recommendations to physicians who provide information or services through online sites. The recommendations maintain that physicians responsible for health-related information should ensure that it is accurate, timely, reliable, and scientifically sound. Also, advice to online users with whom physicians do not have pre-existing relationships or the use of decision-support programs that generate personalized information directly transmitted to users should be consistent with general and specialty-specific standards. In particular, these standards should address truthfulness, protection of privacy, informed consent, and disclosures including limitations inherent in the technology. Finally, physicians who establish or are involved in health-related online sites must minimize conflicts of interest and commercial biases and, if patient specific information is transmitted, they must provide high-level security protections, as well as privacy and confidentiality safeguards.

Keywords

Internet, websites, online sites, e-mail, patient-physician relationship, electronic communication.

Introduction

The Internet is “an interconnected system of networks that connects computers around the world via the TCP/IP protocol” (The American Heritage Dictionary of the English Language 2000) and which provides information and visual content to users. Online sites and online software providers (e.g. America Online) can vary in their sophistication, some allowing for audio-visual transmission, others allowing only for text communication through means such as electronic mail (e-mail), private chat rooms, online discussion groups (also known as Usenet groups), and instant messaging.

It has been estimated that more than 10,000 online sites contain health information on the Internet (Medical Practice Communicator 1999). Individuals turn to the Internet to find information quickly and efficiently. However, many ethical concerns have been raised regarding medical information and services on the Internet. This

report will address those ethical concerns.

Health-related Online Sites

Health-related online sites, including those developed by physicians, exist in many formats that broadly fall under two categories: informational sites and interactive sites. Informational online sites often provide a wide range of information including information related to physicians' practices (see for example AMA's Doctor Finder at <http://www.ama-assn.org/go/doctorfinder>), or information regarding certain medical conditions or specific treatment options. These informational sites are not intended to offer individualized diagnostic or therapeutic advice to online visitors. In contrast, interactive sites may provide a forum for individuals to request specific health information. These sites may specify that questions are reviewed by health care professionals, including physicians, or may provide the e-mail addresses of participating physicians whom individuals can contact for additional information. Other interactive online sites facilitate only the exchange of administrative information, such as appointments, rather than medical information.

Consumer Use and Expectations

Increasingly, individuals seek online consultations through health-related online sites (see for example Johns Hopkins Radiosurgery website at <http://www.hopkinsmedicine.org/radiosurgery>). According to a 2001 survey by Cyber Dialogue, Inc., approximately 3 million people used the Internet for online consultations with a medical expert. By using the Internet, online visitors can eliminate geographic or logistical obstacles in obtaining medical information (Kowalczyk 2001). For example, a recent survey revealed that 41% of patients participating in the study were reluctant to spend time in physicians' offices to ask questions that could be answered through other means of communication, such as e-mail. The survey also concluded that 81% of the online population would like to receive e-mail reminders for preventive care and 83% would like follow-up e-mails after a visit to their physicians (Information Technology Association of America 2001).

Patients may obtain second opinions through online sites. For example, the Cleveland Clinic established e-Cleveland Clinic (<http://eclevelandclinic.org>), an Internet site through which expert review of medical records and diagnostic tests can be sought to obtain a second opinion. Individuals enter a secure online site and fill out an online questionnaire that documents their medical condition. They also are asked to submit necessary information, such as medical records or test results, through the site. Within a few days, individuals receive an e-mail message instructing them to access the secure online site to read the second opinion.

The second opinion provided by e-Cleveland Clinic is accompanied by a disclaimer, which explicitly states that it is offered without the benefit of information usually obtained during a face-to-face encounter or through a physical examination and, therefore, that important information on which the second opinion was based may have been missing. In light of this limitation, the e-Cleveland Clinic strongly encourages second opinions to be shared with the requestor's treating physician. When mandated by law or requested by the patient, the second opinion is directly sent to the treating physician. In such circumstances, the second opinion is rendered within an established patient-physician relationship. However, in the absence of communication with the treating physician, providing a second opinion via a health-related online site can be problematic. Specifically, there may be an increased risk of misdiagnosis or an inappropriate treatment recommendation due to the absence of more complete information, which usually is obtained when there is an established patient-physician relationship.

Interestingly, there are important differences between consumer and physician expectations regarding the function of health-related online sites. A study of patient use of health-related online sites found that although the number of health information consumers was climbing, the satisfaction of the users was declining. The survey revealed that more patients wanted to use the Internet to communicate with their physician. More specifically, patients wanted advice and services from their physicians while online and were disappointed when their physicians resisted e-mail communication (Blumenthal 2002). A 2002 survey found that only 26% of online physicians used the Internet to contact patients. These results illustrate a challenge for patients and physicians: how to use the Internet as a supplement to the patient-physician relationships.

Physician Online sites

While 89% of physician respondents to a 2002 survey use the Internet for some clinical purpose (Blumenthal 2002), approximately 30% of physicians have their own online site (American Medical Association 2002). Many physicians develop interactive online sites for administrative purposes in response to patient preferences (Howell 2002). Online sites that allow patients to schedule or cancel appointments, or to obtain prescription renewals or a referral appear to reduce the number of requests that account

for 80% of physicians' daily phone calls (Kossler 2001).

Besides addressing administrative functions, some physicians establish or participate in interactive online sites that provide medical information. For example, some online sites facilitate general dialogues related to a medical condition. These online sites enable patients to ask specific medical questions. This may occur in the form of real-time dialogues with therapists, primary care physicians, or other medical specialists. In some instances, however, a computer response is generated that may contain a diagnosis and treatment recommendations, without any direct physician involvement (Miller and Derse 2002).

Also, there are interactive online sites that offer prescription drugs to patients. For example, one online site uses board-certified primary-care physicians from Illinois and Indiana to diagnose and prescribe medication to individuals in those two states. The online site uses a triage system to separate minor illnesses from serious conditions and only offers online assistance for acute, minor illnesses. Individuals with serious or life-threatening conditions are advised to seek immediate medical attention (Woods 2002; Carrns 2002). Patients are charged for the services and consultation they received.

Most people pay out-of-pocket for online services. However, to encourage cost-effective physician contacts, several health insurance companies are considering reimbursements for health care services rendered over the Internet (Chin 2002).

Quality Standards and Guidelines

The quality of health-related online sites and the reliability of the information that is provided vary considerably. Individuals can find many highly sophisticated Internet resources that are sponsored by well-known entities such as reputable medical institutions, which will generally offer reliable information or services (Ferguson 1998). Other sites may appear very similar but offer incomplete or outdated information, propagate false information, or dispense services that are unregulated. Some sites may be sponsored by entities with a financial interest in the information or services provided. Yet, they may not appear as commercial sites to some users.

Although only 2% of online users know someone who has been seriously harmed by online site-based medical advice or health information (Shaw 2002), the quality of health-related online sites is a concern for many online visitors and physicians. In a 2001 study, it was found that a majority of health-related online sites that had been reviewed lacked completeness in information and accuracy (Eysenbach et al 2002). Furthermore, a recent worldwide inspection of online sites uncovered more than a thousand sites that make false claims or provide misleading information (Eaton 2002).

Guidelines exist to protect online visitors and physicians when using interactive online sites. The Federation of State Medical Boards created guidelines for physicians who offer health-related online sites, emphasizing five ethical standards: candor, privacy, integrity, informed con-

sent, and accountability (Federation of State Medical Boards 2002). Overall, information contained on physician online sites should be truthful and not misleading or deceptive. Also, physicians have an obligation to disclose information that could influence patients' understanding or use of the information, including financial, professional or personal conflicts of interest (Federation of State Medical Boards 2002).

In December 2002, a consortium of medical societies and medical liability carriers concluded that physicians should engage in online consultations with previously established patients only and that existing standards from the eRisk Working Group for Healthcare were updated to discourage the online treatment, diagnosis, or prescription of medications to unknown individuals (Medem and eRisk Working Group on Healthcare 2002). These new standards were based on disciplinary actions that had been taken by some licensing boards against physicians who had offered medical treatment to unknown, online patients (Chin 2002), and were intended to provide uniform standards for all state licensing boards.

Other forms of protection for users of health-related online sites include the work of the American Accreditation HealthCare Commission (formerly known as URAC), which accredits health-care sites (see <http://www.urac.org>). This accreditation process is based on the ethical standards set by Health Internet Ethics (Heath Internet Ethics 2003), which address privacy, security, quality of information, fairness of transactions, and professional conduct. Thus far, 16 health-related online sites have received accreditation by URAC (Landro 2002). Unfortunately, only 19% of Internet users find accreditation "very important" and only one-quarter of online users follow guidelines for checking the sources and timeliness of an online site's information (Landro 2002). Many consumers tend to focus on the style or the "look" of an online site rather than the accuracy or reliability of its content (Forster 2002).

To address security and privacy concerns, the AMA Internet ID provides a reliable authentication technique and also protects patient and physician information when it is sent or received over the Internet (Council on Medical Service 2001). This feature alleviates many worries that have been voiced by both patients and physicians. Also, the AMA has issued guidelines for all AMA-affiliated online sites to address content definitions, privacy and confidentiality concerns, funding and sponsorship, and content quality (Winker et al. 2000).

Finally, many health-related online sites include disclaimers. These disclaimers often make clear the physician's scope of responsibility and the intent of the provided health information. However, disclaimers do not absolve physicians from their responsibility to patients or their responsibility to provide reliable and factual information.

Ethical Considerations

Interactive as well as informational online sites may raise

ethical concerns, including accuracy, the credentials or qualifications of web-based physicians, conflicts of interest, and advertising. Moreover, the security, privacy, and confidentiality of information transmitted to and from interactive online sites, including those limited to administrative functions, must be considered.

Accuracy, Qualifications, and Standard of Care

In regards to online sites that provide health-related information, both online visitors and physicians are leery of the accuracy of the information. To alleviate these concerns, information presented on online sites should identify the source of their information and be updated frequently since outdated information can be misleading and harmful. When physicians develop their own sites, they should strive to make information easily accessible to the patient population they generally serve, particularly in relation to patients' levels of health literacy and proficiency in English.

It is also important that information regarding credentials or qualifications of web-based physicians be accurate. To the extent that interactive online sites could constitute the practice of medicine, participating health care professionals should bear in mind that the practice of medicine by an unlicensed person is unethical (Council on Ethical and Judicial Affairs 2002, 48), as well as illegal.

Health-related online sites that provide medical advice or care outside an existing patient-physician relationship and without information from a physical exam, or that rely on computer-generated responses, are also ethically problematic because of the increased risk of misdiagnosis or inappropriate treatment recommendations. Therefore, physicians should refer to general and specialty-specific standards regarding the appropriate use of interactive online sites, including their possible use in the absence of a pre-existing patient-physician relationship, as well as the use of algorithms that may generate diagnoses or prognoses that are directly transmitted to users.

Conflicts of Interest and Advertising

When establishing or participating in an online site, physicians should consider any potential conflicts of interest that could emerge, particularly when the site is commercially sponsored or offers commercial services. To this end, the AMA's *Guidelines for Medical Information Websites* maintains that all sponsorship or funding of online sites should be clearly indicated and any advertising should be easily distinguished from and should not be clinically related to the content of a webpage.

Existing guidelines from the AMA's *Code of Medical Ethics* concerning conflicts of interest or commercial biases also apply to health-related online sites. These guidelines include the prohibition against the provision of unnecessary service or the limitations on self-referral and the sale of products (Council on Ethical and Judicial Affairs 2002, 39, 80, 102-103). Also, when making promotional claims on their online sites, as with other forms of advertising, physicians must be mindful of Opinion E-

5.02, "Advertising and Publicity."

Security, Privacy, and Confidentiality

When establishing or participating in interactive online sites, physicians must consider security and privacy concerns. This also applies to the use of interactive online sites that are limited to administrative functions, since they are likely to include personal information such as the patients' name or address, or even a diagnosis or other sensitive information. Physicians who establish or participate in online sites through which they answer e-mails from individuals should follow the ethical guidelines provided in CEJA Report 3-I-02 (Bovi and CEJA 2003), "Ethical Guidelines for the Use of Electronic Mail between Patients and Physicians."

Conclusion

Health-related online sites offer a wide range of information and services and are used by health professionals, patients, and the public with increasing frequency. While there is great hope that the Internet can become a reliable resource for health-related matters, it is necessary to remember that currently it is largely unregulated. Therefore, it is important that physicians who establish health-related online sites or are involved in the provision of information or services through them must adhere to guidelines issued by professional groups. These standards will ensure that online sites are used in a manner that is beneficial to patients rather than fraught with potential harm. In time, with assistance from their physicians and information provided by health online site accreditation agencies, patients may learn to optimize their use of health-related online sites to find reliable information. It also may be possible for patients to receive services in a manner that is efficient, does not compromise their health, and enhances the personal encounters and ongoing personal relationships upon which the therapeutic alliance has traditionally been founded.

Recommendations

The Council recommends that the following be adopted and the remainder of the report be filed:

1. As Internet prevalence and access rapidly increases, individuals turn to the Internet to find health-related information quickly and efficiently. Online users can access innumerable informational or interactive online sites, many of which are maintained by physicians or rely on their services. Physician involvement should be guided by the following considerations:
2. Physicians responsible for the health-related content of an online site should ensure that the information is accurate, timely, reliable, and scientifically sound, and includes appropriate scientific references.
3. The provision of diagnostic or therapeutic services through interactive online sites, including advice to

online users with whom the physician does not have a pre-existing relationship or the use of decision-support programs that generate personalized information directly transmitted to users, should be consistent with general and specialty-specific standards. General standards include truthfulness, protection of privacy, principles of informed consent, and disclosures such as limitations inherent in the technology.

4. When participating in interactive online sites that offer email communication, physicians should follow guidelines established in Opinion 5.026 "Use of Electronic Mail."
5. Physicians who establish or are involved in health-related online sites must minimize conflicts of interest and commercial biases. This can be achieved through the development of safeguards regarding funding and advertising that require disclosure and honesty. It also requires that physicians not place commercial interests ahead of patient health; therefore, physicians must not use health-related online sites to promote unnecessary services, refer patients to entities in which they have ownership interests, or sell products outside of established ethical guidelines. (See Opinions 2.19 "Unnecessary Services," 8.032, "Conflicts of Interest: Health Facility Ownership by a Physician," 8.062 "Sale of Non-Health-Related Goods from Physicians' Offices," and 8.063 "Sale of Health-Related Products from Physicians' Offices"). Promotional claims on online sites must conform to Opinion 5.02, "Advertising and Publicity."
6. Physicians who establish or are involved in health-related online sites that use patient specific information must provide high-level security protections, as well as privacy and confidentiality safeguards. ☺

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